

User Experience Design Guidelines for Telecare Services

Bruno von Niman^{1,2,3}, Torbjørn Sund^{1,2}, Alejandro Rodríguez-Ascaso^{1,2}, Steve Brown¹ and Paul Garner²

*ETSI Specialist Task Force 299¹ (following development in STF 264²)
560, Rue des Lucioles, Sophia Antipolis, France*

¹hf_telecareUX@etsi.org and <http://portal.etsi.org/stfs/hf/STF299.asp>

²<http://portal.etsi.org/stfs/hf/STF264.asp>

³ STF264 (and 299) Leader bruno@vonniman.com

Abstract

Telecare is a strategic enabler for the provision of independent living to older people in their own homes in Europe, driven by demographics and new technologies. The number of elderly people and people with special needs is growing rapidly, requiring dedicated supportive efforts for those unable to cope with every day's technology. For the elderly population, access to Telecare services is important but often difficult due to their lack of familiarity with ICT. With the technical development offering seamless and more continuous access to fixed and mobile broadband networks, the vision of a world where ICT resources around us improve the quality of our lives becomes realistic. New applications and services can increasingly be used to perform necessary tasks and activities of daily living.

The present paper introduces the user experience and usability aspects of telecare services, related challenges and recommended design guidelines applicable to a wide range of telecare solution elements, addressing key characteristics and the interactions between them and the primary (client) and secondary (carer) users, under development in ETSI, co-funded by the European Commission and EFTA.

Key words: e-Inclusion, Service, Telecare, User experience.

1. Introduction and background

The changing demographics of Europe indicate a development towards a population getting older and living longer than ever before.

The aging of our society has unveiled the problem of dependency, as the number of dependant citizens is increasing, especially at the higher levels of the population pyramid. The majority of the dependant population receives informal care, but the population of informal carers is decreasing and aging. These facts may be causing the decrease of the family support to elderly people and people with disabilities and therefore demanding new paradigms to provide support to dependency and independent living.

According to the United Nations Developing Programme, better health care services are required on a global level, but its costs and expenses are not allowed to continuously increase

(without a collapse of the system in the aging Western world). It is estimated that in 2051, 40 % of the European population will be 65 years or older.

Responding to demands for better healthcare raised by an aging population can increase the cost pressure at a time when health care spending is already on the increase. In 1970, the healthcare-related spending of the Organization for Economic Co-operation and Development (OECD - www.oecd.org) countries averaged 5 % of GDP. This increased to 7 % in 1990 and is more than 8 % at present. In addition, it exceeds 10 % in Germany, Sweden, Switzerland and the United States.

More than 75 % of all OECD health spending is publicly financed. Based on assessment of countries' experiences, analysis of underlying issues and review of evidence and in order to control the increasing pressure, OECD recommends actions including the introduction of automated health-data systems, strategies making use of new technologies and improved quality of care through better information.

The European Commission encourages EU Member States to seek a balanced status among the detected needs of providing quality care and social services to citizens, being compliant to standards, containing costs at a national level, and managing services at a local level. "e-Health is today's tool for substantial productivity gains, while providing tomorrow's instrument for a restructured, citizen-centred health system and, at the same time, respecting the diversity of Europe's multi-cultural, multi-lingual health care traditions". A key ambition is better care services at the same or a lower cost.

Delivering traditional health care services to these user groups would lead to a considerably increased cost at a questionable perceived quality, as these clients expect freedom of choice, mobility and personal attention on demand, see ETSI TR 102 415 [1]. In addition, as mobile and broadband communication technologies mature and the average user knowledge level is considerably increased, these clients have an already established experience and trust in the use of more sophisticated ICT products and services.

Human factors and the user experience related to the delivery of health and social care to individuals within the home or a wider community, with the support of systems enabled by ICT is a complex area. It involves a large number of influencing elements, including the establishment of human confidence, device setup, configuration, calibration and maintenance, data collection, user procedures, cultural issues such as the use of language and illustrations, the organization of the care provisioning process, and communication with diagnostic systems and carers, human communication and confirmation and decision making, the presentation medium and accessibility issues.

In addition, as telecare services can be used not only in, but also outside of homes, usability aspects relating to the specifics of mobile environments and equipment and service use need to be covered.

Last but not least, these services must be used by young, older, impaired and disabled people [2-3] and therefore, designed accordingly!

2. Telecare- its past, present and outlooks

In accordance with TR 102 415 [1], the following definition applies:

“Telecare is the provision of health and social care services to individuals, within or outside of their homes, with the support of systems enabled by ICT”.

The main aim of telecare is to reduce the need for hospitalization and institutionalization and refers to cases where services are provided to an end user, it can thus be classified as a kind of business-to-consumer service.

Telecare should clearly be distinguished from *telemedicine*, customarily defined as the use of ICT to support cooperative work between health professionals, a business-to-business service.

Telecare services include health-and social care related information provided through the telephone or the Web, automated appointment reminders, client monitoring services at home or on the move, the identification of emergency situations, et cetera.

In a historical perspective, medical treatment, cure and care until the mid-1900s used to be provided by trained (or at least, experienced) physicians in the client's home; family and neighbors often acted as nursing and supportive staff.

During the development of modern life of the 20th century, this healthcare model has changed quickly and dramatically. Medical care is nowadays most often care unit-centric, often requiring access to advanced medical equipment. A General Practitioner or specialist Medical Doctor's visit to the client's home has become an unusual service.

As a measure to overcome distances, telemedicine was introduced in the 1960s as isolated, stand alone efforts. The first community alarm services were introduced at the University Of Nebraska College Of Medicine in 1959. This was soon to be followed by telephone- or videoconference-based televisit services, as documented in.

Social care services have been supported and extended by Information and Communication Technologies (ICT) during the last 10 to 15 years (through e.g. call centre based services, home equipment for social alarms, etc.). The underlying technology, as well as the availability of these services, did not change much during the last decades.

The widespread deployment of telecare services was held back by factors such as the:

- Lack of efficient and reliable telecommunication networks and devices with the necessary capabilities;
- Unavailability of hardware and software at reasonable costs;
- Lack of on-line connectivity;
- Relatively stable demographics;
- Lack of political conviction, initiatives and support;
- Lack of client trust, acceptability and client expectations and habits;
- Resistance from healthcare professionals (social patterns take generations to change);
- Lack of proven outcome benefits.

Users were not ready yet, nor were the prerequisites- technology, society, technical infrastructure, practitioners, procedures, budgets, et cetera- available and established for a successful deployment.

The proliferation of fixed and mobile broadband services in and outside the home is opening up opportunities for the delivery of telecare services. Thereby, the demand for end user (client) centric human factors guidelines addressing design, development, deployment, use and maintenance of telecare services is on the increase.

In the 1990s, digital technology enablers (infrastructures, terminals and services) became available to the mass market. At present, demographic changes, limited resources, high user expectations, globalization and technology are transforming medical and social care systems in many countries. The penetration of ever-smarter devices connecting to mobile communication networks and the World Wide Web through fixed and mobile Internet, combined with society-oriented, Europe-wide initiatives, health and social care service providers' support, evidence of the existence of demographic and economical feasibility enablers, accepted changes in the delivery of health and social care services and the progress achieved in the area of medical technologies, pharmaceuticals and disposable products enable the deployment of telecare services.

3. A European e-Health area under construction

The European Commission's *eEurope* action plan has recognized that the potential of the Information Society (IS) "...is growing due to the technological developments of broadband and multi-platform access". Furthermore, *e-Health* has been identified as one of the priority objectives of the *eEurope* 2005 Action Plan.

The milestones required to build a "European *e-Health* area" have been defined on four levels:

1. *Basic level*: by mid-2004, a European Health Identity Card (EHIC) shall be introduced (already achieved);
2. *National level*: by 2005, EU member states are required to develop national and regional *e-Health* strategies;
3. *Interoperability level*: by 2006, national healthcare networks should be well advanced in their efforts to exchange information, including client identifiers;
4. *Networked level*: by 2008, health information and services such as *e-prescription*, *e-referral*, Tele-monitoring and Telecare, are to become commonplace, accessible over both fixed and mobile broadband networks.

4. Our approach

Our approach to telecare services builds on the framework described in [1], whereby personal monitoring, security management, electronic assistive technologies and information services are used to support personal health and well-being.

Telecare is generally associated with care of older people, however it has been shown that it is applicable irrespective of age. In addition telecare may empower people with sensory, physical, cognitive or other impairment(s), temporary or permanent. Telecare solutions must embrace the philosophy of design-for-all, promoting accessibility by as large proportion of end users as possible. Complementary solutions based on assistive technology must be available, when required.

Human factors and the user experience of telecare services involve the consideration of many factors, including user confidence, device setup, configuration, calibration and maintenance, data collection, user procedures, cultural issues such as the use of language and illustrations, the organization of the care provisioning process, and communication with diagnostic systems and carers, human communication and confirmation and decision making, the presentation medium and accessibility issues.

In addition, as telecare services can be used not only in but also outside of the home, usability aspects relating to the specifics of mobile environments and equipment and service use need to be covered. Last but not least, these services must be usable to young, older people, impaired, disabled or temporarily ill people.

By means of user experience, telecare services can gain considerable benefits from applying human factors expertise. We foresee that our work can have a major impact on several important stakeholders and areas:

- For **clients**: understandable and usable set-up procedures and user guides for telecare terminals and services, resulting in increased user satisfaction and inclusion of all users including those with special needs; improving their confidence in the use of telecare services, and thereby supporting their independent living style.
- For **carers**: improving efficiency and satisfaction of both formal and informal carers, when using telecare services.
- For **health and social care providers**: providing them with guidelines for taking users' views into account, and therefore improving their efficiency when adopting new Telecare procedures.
- For **manufacturers, designers and developers**: references to generate products and services which are closer to the needs, abilities and preferences of users, thereby reducing unnecessary risks and experimentation inherent in the lifecycle of a product or service.
- For **public administration**: support on decision taking during public procurement processes.
- For the government: support the expansion of Telecare services.

Medical devices have traditionally been designed for use by professionals, in hospital environments, and coming with an extensive training programme. With telecare, medical devices may require handling by the clients themselves, who are non-professionals, often with little or no training in using complex electronic devices. This requires a change in the mindset of the designers of medical equipment, so that a default workable configuration, fail-safe operating procedures, compatibility with other electronic equipment in use and set up and self-documenting without requiring manuals become a default part of the process.

There are opportunities to create additional benefits for clients, by integrating home safety monitoring and control with both health and social care oriented telecare services. For maximum usability of telecare services by the general population, more effort should be put into the design of hardware and user interfaces, with close attention paid to the opportunities of creating a single user interface, applying generic UI elements to control multiple applications and services for the client, carer or coordinator. Services must be designed to be fail-safe, not promote excessive dependency and be controllable remotely by carers or coordinators, when appropriate.

4. Stakeholder's dimensions, guideline areas and structure

The user experience ETSI Guidelines under development will address four categories of end users: patient users (clients), care service providers, buyers and procurement and developers and (infrastructural) access providers.

There exist three main categories or dimensions of aspects to consider when approaching user experience of telecare services- these are covered through:

- Telecare service life-cycle stages, through the structure of the clauses providing:
 - Research and specification, design & development, testing, manufacturing, service deployment, setup & configuration, service provisioning and initial use, service maintenance and replacement guidelines; and
 - additional usability, accessibility, mobility, interoperability and personalization guidelines.
- Stakeholders, covered by the structure of the guidelines; and
- Human factor characteristics, addressed through the content of the guidelines.

Due to the complexity of telecare services and the numerous solution elements involved in the design, delivery, setup, configuration, use and maintenance of telecare services, the human factors and usability of telecare services must cover such aspects as the ergonomics of physical devices, compatibility and complexity of equipment and services, UI aspects, set-up and configuration, user education and training, price and cost transparency aspects, communication terminals, network access and applications.

One of the most important goal of human factors, usability and accessibility activities in telecare is anticipate use cases and provide design solutions to eliminate errors that could cause harm to the client or to the carer. In order to be able to achieve this goal under the various constraints and user requirements, user centred design and development approaches play a very important role. Telecare services should not be technology driven but user centric.

5 Ethical, privacy and security aspects of telecare services

In order to illustrate the width and complexity of the user experience of telecare services, let us examine the related ethical, privacy and security aspects.

The use of information technologies in the home raises ethical questions concerning privacy, security, freedom of choice, dependency and consent, particularly important in the development of systems for people who are not able to control the technology themselves - for example, people with dementia or other mental impairments.

Several strategies could improve the ethical and non intrusiveness aspects of telecare services. Recommendations and guidelines are under consideration for:

- Respect of the privacy of users;
- Minimize intrusion when introducing telecare services and during the collection and use phases of client data (personal or gathered from monitoring systems);
- Avoid the use of technical language, as this may interfere with the understanding of telecare services;

- Take into account the role of relatives, friends and people providing informal care, and its implications in Telecare service provisioning;
- Reduce the impact of the equipment in homes, by adapting the design, behaviour and other characteristics of relevance to the home environment;
- Present telecare services and systems as tools of self-empowerment, rather than as an outward sign of dependency on external services and aids;
- Telecare services should be promoted in ways affirming positive views of the service;
- Regarding the independent living style for disabled people, feasibility of telecare services should always be offered as a complement or alternative to healthcare services delivered by human beings; and
- Ethical codes of care professionals should be made applicable to all Telecare services.

Privacy is not just about hiding information or confidentiality but also about control, autonomy and integrity. It is the right of people to control what personal information should stay inside their own house and what can be distributed to the outside world. It is as well the right to control for which purpose personal information should be collected, maintained and used. Providers of telecare services need to make sure that the user right to privacy will not be lost and that technology advancement can be developed alongside privacy interests.

As a baseline, it could be expected that people's negative attitudes to privacy will reduce as the benefits and inevitability of living with pervasive sensing and computing technologies becomes more apparent. However, whilst the benefits of some aspects of telecare are compelling and immediate (e.g. the monitoring of cardiac arrest amongst high-risk patients), the benefits of "mass-market" (mostly preventive) telecare services are far less tangible or immediate. It is the growth of the latter applications that is in greatest danger of being severely restricted by privacy concerns.

Although telecare solutions in the EU will need to conform to relevant European and national regulations and laws (governing, for example, data protection), it seems unlikely that these alone will be sufficient to allay the privacy concerns of most users. For telecare solutions to become truly acceptable to a larger number of people, technology and service providers have to develop products that consider both security and privacy practices. The risks should be assessed and appropriate security measures and well-known practices should be defined to maintain the risks under an acceptable level. The aim is to increase the client involvement and allow the client to have more interaction with and control over the information about his status and behavior with the final goal to improve the overall trust on the system.

In [1], the following recommendations are made:

- The client should be given clear notice of the presence of telecare technology in their environment;
- The client should be given the opportunity to engage and interact with their personal information and to understand the benefits of telecare technology;
- There should not be any prohibition on clients to control their personal information;

- The telecare system should provide to the client a clear and complete access to the personal information collected;
- Telecare technology should not be deployed to monitor and identify people that are not directly associated with a telecare service;
- Telecare services must not be exploited in any case for marketing purposes, or to collect or derive personal information about consumer product habits;
- Information must be collected and distributed in a secure way;
- Measures should be put in place to ensure compliance to the regulations. The client should be able to complain where its privacy has been violated.

Two distinct challenges are identified in terms of privacy and security:

- It is necessary to ensure that a client is monitored with the correct security requirements, and also that the data collected cannot be eavesdropped or accessed without authorization.
- Personal information must be securely shared among multiple carers, public health services and private enterprises. Privacy concerns about information flows across multiple domain of ownership or control can stop stakeholders in participating in data sharing. Users will be concerned about the likelihood of that party keeping the information very secure, and to only use the information for its intended purpose.

There are three non-exclusive strategies to follow, addressing telecare service user's privacy concerns:

- Keep the information as local as possible;
- Give control to the user; and
- Promote industry privacy standards.

In addition, it is recommended to consider defining the information required, not only to the understanding and control of personal information, but also to the operators who must fulfill such roles in collaboration with different entities. As a simple example, it would probably be beneficial to standardize the information sent to various emergency services in the event that the system detects an emergency.

Central to several of the above recommendations are the high-level issues of enabling users to have simple and comprehensive control over the privacy of their personal information and ensuring that their personal information is only shared with the correct people/organizations.

References

- [1] ETSI TR 102 415: "Human Factors (HF); Telecare services; Issues and recommendations for user aspects".
- [2] European Commission, Directorate General Information Society: "Report from the Inclusive Communications (INCOM) subgroup, Working Document (January 2004)".
- [3] CEN/CENELEC Guide 6: "Guidelines for standards developers to address the needs of older persons and persons with disabilities".